

APPENDIX D

United States v. Nebraska, No. 8:08-CV-271 (RGK)

Nebraska Department of Public Health Emergency Evacuation Order

On January 31, 2009, the State's Director of Public Health, Joann Schaefer, M.D., ordered that residents who are "medically fragile" be permanently removed from BSDC because she had determined that BSDC was unable to deliver effective health care services and would not be able to meet their complex health needs.¹

In the emergency order, Dr. Schaefer set out a definition of "medically fragile"; the State then determined that 47 BSDC residents fell within the definition. Dr. Schaefer directed that these medically fragile persons be transferred to alternate settings within one week of her order – by February 6, 2009. She also placed restrictions on BSDC serving medically fragile persons going forward. Well in advance of the deadline, the State discharged the 47 individuals to one of four hospitals in Omaha or Lincoln.

On February 18, 2009, the United States sent the State a letter detailing concerns and notifying the State that it expected prompt and effective steps to ensure the health, safety, and welfare of the discharged residents. The United States pushed the State to promptly develop community alternatives to the hospitals. From February 23-27, 2009, representatives of the United States accompanied the original monitor on visits to all 47 people at each hospital site.

At the time, there were few good options to address the needs of the group. The Public Health director had decreed that BSDC could not serve them, and, given that the Agreement was still in its first six months, the State had not yet developed sufficient community capacity to meet the needs of persons with complex health conditions. There were insufficient specialized providers in the community, the State's waiver was inadequate, and the State's community monitoring and technical assistance infrastructure was lacking.

Within the first few weeks of the emergency evacuation order, hospital representatives began to meet with family members and guardians to plan for discharge; given that there were few community options, family members and guardians gravitated to private nursing homes as an alternative to the hospitals. This ran counter to the terms of the Agreement; the parties had agreed that nursing homes are not well-suited to provide care and services for people with DD.

The United States worked with the State, prompting it to take steps to halt this practice and to work to develop integrated community settings that could deliver needed services and supports. Prior to this, the State had allowed the transfer of about half of the discharged individuals from hospital settings to nursing home settings. By mid-April of 2009 though, the State had stopped placing anyone from the hospitals into nursing homes.

¹ Dr. Schaefer was appointed by the Governor, but she was independent of the State's DD agency. Neither the United States nor the State's DD agency had any advance notice of the Public Health director's decision to issue this emergency evacuation order.

Over the next several months, the State accelerated its efforts to address the needs of this group. Among many things, the State:

- entered into a multi-million dollar contract with a local community provider to build and staff at least 11 new homes throughout the state specifically to meet the needs of dozens of persons with complex health care issues; the State opened the first of these homes in April 2010;
- entered into separate contracts with community specialists to provide needed health care (and behavioral/habilitation) expertise to community providers supporting persons with complex health care needs; and
- developed an online data and information system to improve the quality and timeliness of communication between and among various key actors throughout the system.

Over 70 percent of the medically fragile group (33/47) was eventually placed in an integrated community setting. Of those still alive today, over 80 percent currently live in community settings.

The emergency displacement of the 47 had a negative impact on most of the group, however, especially for those placed in institutional settings. Within one year of discharge from BSDC, 12 individuals had died; more than two-thirds of them died at a hospital or a nursing home. Over the course of the next six years, only nine people within the medically fragile group died. Seven of the nine lived at BSDC, a nursing home, a private ICF, or an “MSU” (a group home with enhanced medical supports) – so most of those who died lived in more congregate settings. During the six years, only two people died in traditional community waiver homes.